The Impact of Provider Beliefs, Perceptions and Practices on Advance Care Planning Conversations in Seriously Ill Patients

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The Impact of Provider Beliefs, Perceptions and Practices on Advance Care Planning

Conversations in Seriously Ill Patients

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Dedication Page

In memoriam,

To those we’ve lost
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And finally, thank you Tom and Sydney for your enduring patience and love. This year has been one of challenges and loss, yet we have persevered together.

*Storms make trees take deeper roots.*

- Unknown
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Abstract

For clinicians, discussions that focus on life-sustaining procedures and interventions is often easier than partaking in conversations that provoke feelings of inadequacy or uncertainty. This may result in patient-provider miscommunication about end of life preferences and goals of care. The focus of this translational research and clinical project was to examine provider barriers to practice and to implement a structured communication tool using the Serious Illness Conversation Guide when engaging patients and family in advance care planning and goals of care discussions. Previous research has indicated that many clinicians lack formal education and confidence in end of life care discussions. The project consisted of a pre- and post-education survey assessing perceptions, beliefs and practices and a virtual training session that included instruction on the use of the Serious Illness Conversation Guide. Participants included physicians, nurse practitioners and physician assistants in hospitalist and other clinical practice settings. Results demonstrated continued confusion as to who should initiate end of life care conversations, with most participants suggesting patients rather than providers initiate discussions. The findings of this study were consistent with previous literature and support the need for structured education for both physicians and nurse practitioners in advance care planning conversations.

Keywords: advance care planning, end of life, goals of care, serious illness communication, Serious Illness Conversation Guide
Impact of Provider Beliefs, Perceptions and Practices on Advance Care Planning Conversations with Seriously Ill Patients

The Acute Care Nurse Practitioner (ACNP) responds to the room of an elderly woman admitted to the hospital for an acute exacerbation of Chronic Obstructive Pulmonary Disease (COPD). She is found in extremis and attempts to ventilate her with non-invasive positive pressure ventilation are ineffective. Unable to tolerate the mask, she becomes fatigued and progresses to respiratory arrest. Due to the hospital’s hybrid charting system there is confusion over her resuscitation status. Resuscitation measures are initiated, including chest compressions with tracheal intubation and mechanical ventilation. The ACNP speaks with her daughter who admits that her mother’s COPD has been worsening recently and with her advanced age, she would not want to be kept alive on machines, desiring a natural death. After ending the call, resuscitative efforts are discontinued and the patient quickly expires.

The clinical scenario described is not an uncommon occurrence in acute care settings. The acute care nurse practitioner has encountered similar clinical situations in which acutely ill patients with heavy disease burden quickly deteriorate during hospital admission. Lack of code status documentation or an advance directive in the electronic medical record can lead to inappropriate activation of the code team and initiation of cardiopulmonary resuscitation (CPR). It has been the experience of this author that for older patients admitted to the hospital with acute exacerbations of certain serious, chronic diseases, lack of communication and clear understanding of patient preferences, goals of care and end of life wishes can result in unwanted life-prolonging measures.

Approximately 209,000 adults per year experience cardiac arrest during hospital admission; despite improvements, risk-adjusted survival remains low with only 22.3% of adults
surviving to discharge (Kronick et al., 2015). Reasons for low survival rates are most likely multifactorial and include variability across hospitals and failure to recognize early deterioration (Kronick et al., 2015). Furthermore, patients in the hospital transitioning to palliative care or that are actively dying, often lack clear Do Not Resuscitate (DNR) orders and may undergo a failed resuscitation attempt prior to changing to comfort care (Kronick et al., 2015). The importance of provider and patient communication regarding end of life care and subsequent documentation cannot be over emphasized.

The optimal time for advanced health care planning and end of life discussions is prior to critical illness or event. Despite frequent use of hospitals for high acuity illnesses and disease management, only 26.4% of the U.S. population studied in a 2010 national health survey had any form of documented advanced health care planning (Rao et al., 2014). For patients with serious, chronic illnesses such as COPD, congestive heart failure (CHF), and end–stage renal disease (ESRD) who experience frequent exacerbations and hospitalizations, absence of clear goals for future care can be confusing for both patients and providers (Rao et al., 2014, Anderson et al., 2010). Care discussions often focus on prevention of exacerbations and subsequent readmissions but have historically been void of end of life decision-making; however, there is growing awareness around the use of palliative care for progressive chronic disease management (Heidenreich et al., 2013). Certain chronic diseases may cause slow, progressive decline in which advance care planning may be beneficial to address targeted end of life needs (Waldrop & Meeker, 2012). Conversations that are timed on the basis of an acute, critical illness tend to be distressing for care providers, patients and their families and focus on clinical procedures and life-prolonging therapies (Bernacki et al., 2015, Anderson, Kools & Lyndon, 2013, Torke et al., 2011). Patient-provider conversations in the hospital setting often are void of information such as
possible risks and benefits or discussion of prognosis for those with progressive serious illness (Anderson et al, 2013).

**Background**

Current literature suggests that gaps in knowledge, attitudes and practices exists in promoting open communication to meet end of life care needs between health care providers and patients. You et al. (2014) reported that 80% of older adult Canadian patients, preferred a patient-centered and palliative approach to end of life without life-prolonging measures. Literature has consistently reported patients’ preferences for dying at home, yet many individuals spend their final days in the hospital (Virdun, Luckett, Davidson, & Phillips, 2015). Rao (2014) and colleagues concluded that end of life care constituted a national public health issue as the prevalence of chronic disease among adults was increasing. Data from a 2010 study indicated that 73.7% of participants had not made end of life provisions or elected a health care proxy to speak on their behalf in the event of a life-threatening illness (Rao et al., 2014). In a European study cited by Hartog et al., (2014, pp. 128) “95% of ICU patients lack decision-making capacity” yet receive life-sustaining measures such as respiratory and circulatory support, invasive monitoring, vasopressor, transfusions, hemodialysis and other life-saving therapies despite not knowing individual preferences for end of life care.

Torke and colleagues found that in situations that required conversations regarding resuscitation status, surrogate decision makers (58.2%, n = 389) were encountered more often than patient (28.2%, n = 191) only discussions (Torke et al., 2011). Furthermore, patients that required surrogate decision makers, were more likely to have required admission to the intensive care unit (ICU) during the course of the entire hospital stay (Torke et al., 2011). This research highlights the complexities of using a surrogate decision maker to determine end of life
preferences and choosing life-saving measures during critical illness and may cause “ethical and emotional” burdens for decision makers (Torke et al., 2011, pp. 1330).

Also, frequently cited in literature is the concern among patients regarding pain at the end of life, comfort, dignity, and costs of care (Rao et al., 2014). Despite significant concerns with future care, many patients report lack of discussions or plans regarding their preferences of end of life care with providers (Rao et al., 2014). Patients are often willing to discuss advance care planning (ACP) and goals of care, especially if providers initiate conversations; however, discomfort with discussions of prognosis and preferences is a significant barrier (Simon, Porterfield, Bouchal & Heyland, 2013). The disconnect between individual preferences, desires and actual care received is notable, and can only be improved upon through communication between patients and health care providers.

**Statement of the Problem**

In 2010, there were over approximately 30 million people living in the United States greater than 65 years of age with multiple, serious illnesses including hypertension, congestive heart failure, chronic obstructive pulmonary disease, chronic kidney disease, and others (Institute of Medicine, 2014). Conversations regarding advance health care planning and goals of care have been an inconsistent part of chronic and serious disease management by providers due to a general lack of knowledge coupled with provider reluctance to initiate discussions. Shortages of providers specially trained in end of life care will impact the ability for other clinical specialties such as hospitalists and primary care providers to consult palliative care teams to discuss prognosis and future goals of care. (Bernacki et al., 2015, Lakin et al., 2016). Lack of comfort and knowledge have been cited repeatedly as a barrier to engaging in advance care planning discussions with patients (Institute of Medicine, 2014). Furthermore, the unavailability of
organizational support and absence of communication and training standards have contributed to inconsistent provider-patient end of life care discussions (Institute of Medicine, 2014). Proficiency in these conversations will become increasingly important for non-palliative care clinicians, especially in the acute care setting.

A recurrent theme identified in the literature is regarding the training and confidence level in end of life conversations by health care providers. Empowering providers with the skills needed to initiate earlier conversations with patients and families for preferences and goals of care, may help achieve a more patient-centric experience through the endorsement of self-determination and shared-decision making. Improving provider comfort level and confidence with these difficult yet important conversations during hospitalization may improve providing care more consistent with patient values and wishes. As valuable and respected members of the healthcare team, nurse practitioners can proactively initiate conversations with patients and their family regarding goals of care during times of stability rather than health crisis.

**Purpose of the Project**

This project was developed to explore the impact of education on raising awareness and confidence among providers when engaging in advance care planning and goals of care conversations. Assessment of provider perceptions and beliefs that impact end of life care discussions was conducted to identify barriers and facilitators to practice. Implementation of a standardized approach to serious illness conversations was introduced.

**Project Aims**

This project had several aims: (1) to explore perceptions, attitudes, and beliefs of providers regarding end of life planning conversations (2) develop an evidence-based educational intervention for health care providers regarding end of life conversations, and (3) test
hypotheses regarding the effect of the educational intervention on practice as documented in the medical record.

**Review of Literature**

A comprehensive literature search was performed to examine the presence of advance directives for individuals within the acute care setting and resuscitation status. The search yielded mixed results and many of the research articles examined the lack of patient advance directives, timing of DNR orders in acute and critically ill patients and impact of care received during critical illness. The search was further refined to focus on barriers to communication, documentation, serious illness communication, advance care planning and goals of care conversations. The literature search was conducted using the Galileo library system with articles retrieved from CINHAL, EBSCO, OVID, ProQuest, ScienceDirect and PubMed databases. Queries included using various combinations of keywords and phrases to target and narrow results which contained: end of life communication, advance care planning, shared decision making, advance directives, end of life care, barriers, goals of care, documentation, chronic serious illness, barriers to goals, and perceptions of providers. Although the search was limited to English language publications, no limitations were placed on geographic location of the studies. The evidence presented indicates some of the known gaps in literature between knowledge, experience and practice for providers and clinicians engaging in end of life discussions with patients and their families.

**Barriers to Communication**

Literature consistently reports that patients with serious, chronic illness, communication regarding prognosis and goals of care continually are areas of uncertainty, variability and weakness by clinicians. In 1995 a landmark study, the SUPPORT trial was conducted to improve
the communication in seriously ill hospitalized patients (Connors et al., 1995) that identified knowledge gaps between patient preferences for end of life care and the clinical care actually received. The researchers found in their Phase I prospective observational study that there were significant barriers to communication and decision-making between providers and hospitalized patients with serious illness (Connors et al., 1995). Over two decades later, Bernacki & Block (2013) noted that most physicians are more uncomfortable than their patients in discussing end of life care and concerns. This sentiment continues to echo across literature and the focus of what barriers exist and why.

**Lack of education and experience.** To identify common barriers that impede communication and decision-making about goals of care with patients with chronic, serious illness, You et al. (2015) conducted a large multicenter, cross-sectional survey of hospital-based clinicians including nurses, medical residents and staff physicians in medical-teaching units. Among the various findings in this study, was the reported lack of formal end of life training by all clinician groups; 60.3% \((n = 757)\) of all clinicians surveyed indicated no formal education and overall discomfort on the subject including “lack of effective communication skills” (You et al., 2015, p. E6). There was also support for other health care team member involvement including advanced practice nurses in the goals of care discussions and decision-making (You et al., 2015). It is important to note that all clinicians surveyed, ranked patient and family factors as the most common barriers to engaging in end of life discussion (You et al., 2015).

There are a limited number of practicing hospice and palliative care specialists with an estimated future shortfall of providers greater than 10,000 with no projected relief (Dobbins, 2016; Bernacki et al., 2015). Shortages of providers specially trained in end of life care will impact the ability for other clinical specialties such as hospitalists and primary care providers to
consult palliative care teams to discuss prognosis and future goals of care. (Bernacki et al., 2015, Lakin et al., 2016). Lack of comfort and knowledge have been cited repeatedly in literature as a barrier to engaging in advance care planning discussions with patients (Institute of Medicine, 2014). Furthermore, the unavailability of organizational support, and absence of communication and training standards have contributed to inconsistent provider-patient end of life care discussions (Institute of Medicine, 2014). Literature supports the need for proficiency in these conversations for non-palliative care clinicians, especially in the acute care setting.

In 1998, Dr. Mary Stoeckle conducted a non-experimental, descriptive design to assess perceptions regarding end of life care and discussions of physicians, nurses, social workers, and pastoral care associates. Of the total respondents, 91% stated they participate in some part of end of life discussions despite feelings of inadequacies in training or comfort (Stoeckle, Doorley & Mc Ardle, 1998). Only 23.9% of participants reported having formalized training or a course on the PSDA or advance directives despite the directive by the Joint Commission (Stoeckle et al., 1998). Other important findings from this study included the lack of educational training, discomfort with use of words such as death or dying and limited work experiences with end of life discussions (Stoeckle et al., 1998).

There has been limited research specifically examining the role of advanced practice nurses in advance care planning and goals of care conversations. Dube, McCarron, & Nanninni (2015) examined the prevalence and perceived systems barriers and facilitators to conversations with patients and families by nurse practitioners. Utilizing a convenience sample from a statewide database of Nurse Practitioners (NP), researchers invited NPs to participate in a survey to assess personal and professional beliefs about end of life discussions. Stoeckle’s End of Life Care Decision Questionnaire II (EOLCDQII) was slightly modified to accommodate the study
and compare findings from 1998 regarding professional beliefs related to end of life care. The findings were consistent with previous studies highlighting the lack of formal education and comfort among clinicians and providers regarding advance care planning conversations with patients and their families (Dube et al., 2015).

**Patient-provider engagement.** In a large qualitative descriptive study, Simon, Porterfield, Bouchal & Heyland (2015) examined perceptions by patient and their families and identified three themes that influenced advance care planning discussions. Patients and families were more likely to engage in end of life discussions if certain needs were met including having “access to doctors willing to have conversations” (Simon et al., 2015, p. 57). Additionally, the type of interaction between the provider, patient and family was noted to be an important part of engaging in advance care planning conversations (Simon et al., 2015). Timing, location, and quality of the communication all impacted the experience (Simon et al., 2015). Nurse practitioners also reported time as both a facilitator and barrier to conversations about advance health care planning (Dube et al., 2015). These factors are important for shaping future initiatives for ACP and goals of care conversations as literature has shown there is lack of standardization, comfort and training for such discussions. The authors proposed suggestions based on their findings for improving conversations in the acute care setting including: acknowledgement of personal relevance of advance care planning, increasing frequency of conversations by introducing advance care planning in the outpatient setting and building upon that foundation in the acute care setting, formalized education to improve communication skills for providers, and health care infrastructure to provide support to patients and providers by ensuring access to documents across health care settings (Simon et al., 2015, p. 61).
**Prognosticating outcomes.** Difficulty in disease prognostication also causes distress or difficulties in goals of care conversations (Bernacki & Block 2014; Patel, Janssen & Curtis, 2012). Physicians may be “overly optimistic” in discussing prognosis, leading to care decisions by patients that lean towards the choice of more life-saving therapies (Bernacki & Block, 2014, p. E3). In discussing advance care planning with patients with COPD, authors contended that conversations should occur early in the diagnosis; however, admit that timing may be a challenge as it may erroneously signal a change in course or trajectory (Patel et al., 2012). Again, both clinician and patient related barriers have been identified by the authors and include many similar themes noted in previous literature. Lack of education in end of life communication, critical illness or intensive care unit admission providing a poor atmosphere for discussions, and lack of early of advance care planning conversations are cited as common barriers (Patel et al., 2012). Recommendations provided included further research regarding barriers to conversations in patients with COPD (Patel et al., 2012).

**Cultural and spiritual factors.** Diverse populations present special challenges for health care workers in practice. In a mixed-methods study of 1,040 physicians, 99.9% ($n = 1032$) reported barriers to having end of life conversations (Periyakoil, Neri, & Kraemer, 2015). Furthermore, the majority of respondents (85.7%), reported end of life conversations were challenging with diverse or ethnic groups of patients regardless of their specialty (Periyakoil et al., 2015). Six common barriers were identified with language and medical interpretation being the most commonly perceived issue. Spiritual and religious beliefs by patient and families coupled with providers’ lack of understanding of cultural differences were also major concerns and barriers to having end of life care conversations (Periyakoil et al., 2015). This study
highlights the need for education on cultural diversity as well as the importance of having systems and resources in place to assist providers with these difficult conversations.

**Components of End of Life Communication**

Serious illness care conversations within the hospital focus on life-prolonging procedures such as CPR and mechanical ventilation, rather than patient values, preferences and goals of care (Bernacki et al, 2015). The articles reviewed demonstrate the lack of consensus on methods for improving communication or standardization. While barriers are identified and indicate that end of life care training is lacking across provider types, there has been no universal recommendation for promoting patients’ right to self-determination and respect for personal or cultural values in advance care planning. It is important to note that sufficient confusion exists among terms and what constitutes proper documentation of advance care planning conversations. In examining available literature, there is a lack of standardization of the elements of such conversations and how to document they have taken place. It is also important to note that legal documents such as advance directives or POLST forms are not conversations, but records that convey information in a legal and binding manner.

A systematic review of the literature conducted by Sullivan, Ferreira da Rosa & Meeker (2015) examined various studies to enhance understanding of end of life family meetings and their outcomes. Of the 24 articles reviewed, there were 5 mixed-methods, 10 quantitative, and 9 qualitative studies which revealed several common themes, including barriers to effective family meetings and the characteristics of the same (Sullivan et al., 2015). While the authors suggested there is a need for further research regarding structured family meetings, it was identified that focus on effective and meaningful communication by health care providers was more important (Sullivan et al., 2015). In a cross-sectional study of hospital interviews with patients and their
families conducted by You et al., (2014), elements of end of life discussions were examined. Patients and families consistently reported that less than 2 of 11 elements of end of life conversations were discussed. Furthermore, both patients and families ranked “preferences for care in life-threatening illness”, opportunity to discuss prognosis and the ability to ask questions within the top five most important elements of the discussions (You et al., 2014, p. E684).

Although experts have provided 11 key components of end of life and goals of care communication, few are discussed with patients and their families (You et al., 2014). This has been identified as a knowledge-practice gap and may contribute to the disconnect between patient care preferences and actual prescribed care in the acute care setting (You et al., 2014).

In a Delphi analysis performed by Downar & Hawryluck (2010), the purpose was to determine what constituted effective communication when discussing resuscitation status and life support with patients and families. This method consisted of two rounds of surveys to build a consensus among clinical experts regarding timing of conversations, specifics of CPR, influence of personal values and beliefs on decisions, and role of prognostication (Downar & Hawryluck, 2010). After completion of the survey, experts developed recommendations for how code status was discussed. Guidelines included: discussions should occur early or whenever a clinical change occurred with the patient, code status should also be incorporated into goals of care discussions versus as resuscitation discussion, offering prognosis, and describing cardiac arrest and associated therapies (Downar & Hawryluck, 2010, p. 190). It should be noted that these recommendations have not been universally accepted or referenced; authors note they are intended to provide guidelines and not serve as a gold standard (Downar & Hawryluck, 2010).

In a modified Delphi study by Sinuff et al., (2015) researchers attempted to develop definitions and quality indicators for effective end of life communication. Utilizing a 7-point
Likert scale and four rounds, a consensus which included 34 items divided into 4 categories based on conceptual framework that was developed (Sinuff et al., 2015). The categories were advance care planning, goals of care discussions, documentation and organizational and systems. Despite any specific recommendations for components of advance care planning discussions, this work group highlighted the importance of patient-centered communication that is timely and effective for improved care delivery (Sinuff et al., 2015). Associated quality indicators were developed for each category that offers measurable outcomes to evaluate effectiveness of implementation of improvement programs (Sinuff et al., 2015).

In a prospective observational study conducted by Ahluwalia, Levin Lorenz & Gordon (2013), researchers examined how often physicians used key elements of advance care planning discussions in the outpatient setting for patients with advanced heart failure. Using qualitative content analysis, researchers evaluated the number of times physicians used one or more of the three elements of the advance care planning conversations. There were 25 separate instances of discussion during clinic visits (Ahluwalia et al., 2013). Of the responses, there were 17 uses of explaining the course or prognosis of heart failure, 6 instances of eliciting patient preferences for care and 2 encouraging documentation of patient preferences (Ahluwalia et al., 2013). In analysis of their data, authors identified time, not knowing what to say and lack of comfort with the discussion as barriers to conversations (Ahluwalia et al., 2013). Despite providing physicians with the discussion components, explaining, engaging and encouraging, it was recommended that a more organized approach to communication to address the perceived barriers by providers (Ahluwalia et al., 2013).

Research conducted by Bernacki & Block (2014) determined that a combination of patient, physician and system factors exist in the communication difficulties at end of life. For
health care clinicians lack of formalized training is a commonly reported barrier. In addition to the lack of comfort and uncertainty about the conversation, issues such as timing and who is responsible for the discussion impact the process of advance care planning (Bernacki & Block, 2014). Bernacki & Block (2014) suggested that the lack of a systematic approach to goals of care conversations in conjunction with other barriers to communication, opportunities for patients to express their preferences for end of life care are missed. Additionally, the authors recommend the use of a structured conversation guide to assist clinicians with ACP and goals of care conversations.

**Documentation of Advance Care Planning**

Much of what is known about end of life care has focused on improving communication and ensuring patient and family needs are met. It is worthy of mention that while documentation does not equate to quality patient care, it is an important component in the information exchange process. In a prospective randomized controlled trial, researchers sought to examine the impact of advance care planning discussions on the care that patients received while in the hospital (Detering, Hancock, Reade, & Silvester, 2010). While the main focus of this study was to determine if patients’ end of life preferences were known and if they were respected, this information relied on the documentation of information in the medical record. Of the 125 patients that received advance care planning 70 (56%) made care decisions and appointed a surrogate decision maker (Detering et al., 2010). After 6 months, it was determined that end of life preferences were respected for 25 of 29 (86%) patients from the intervention group as compared to 8 of 27 (30%) in the control group (p = <0.001) (Detering et al., 2010). Waldrop & Meeker (2012) also found that while the elements of end of life care conversations may be recorded, advance directives or other care planning documentation must be complete and
accurate. Wilson et al., (2013) examined in a retrospective chart review of 60,105 electronic medical records that while 50.9% had evidence of advance care planning documentation, there was a lack of standardization (Wilson et al., 2013). This was a notable finding as the outpatient documentation could be viewed from the inpatient setting by hospitalists using this particular EHR. This study highlighted the importance of a standardized location to reduce potential errors and reduce the time spent searching for priority information (Wilson et al., 2013).

A retrospective, descriptive, explanatory design was used to examine selected medical records for completeness and timeliness using an electronic health record in an acute care hospital setting (Al Baloushi & Ramukumba, 2015). Included in the document review, discharge summaries and history and physical exams were assessed each for both timeliness and completion (Al Baloushi & Ramukumba, 2015). For discharge summaries, there was 86% compliance for timeliness with 34% compliance for completeness; additionally, these summaries were missing most of the seven required documentation elements (Al Baloushi & Ramukumba, 2015). Documentation compliance for history and physicals had similar compliance for completeness of 56% and timeliness of 83% (Al Baloushi & Ramukumba, 2015). Deficiencies were attributed to system design and human factors (Al Baloushi & Ramukumba, 2015). In an exploratory study reviewing the clinical resuscitation notes of 99 elderly patients in an acute care setting, reviewers found that the 50 patients that had the capacity to talk about resuscitation matters at admission, only 32% ($n = 16$) had documentation of preferences in their medical record (Brown, Ruberu, & Thompson, 2014). Through continued case review, 34 patients were identified as having resuscitation decisions documented with evidence that a discussion occurred with the patient, family or both in 26 of 34 patients (Brown et al., 2014). In seven of the total cases with documented resuscitation preferences, it was noted that documentation was difficult
to read, lacked uniformity, consistent terms and abbreviations were unclear (Brown et al., 2014). Despite documentation from previous hospitalizations, patient preferences for resuscitation were not documented on the current visit for some admitted patients further highlighting the need for communication guidelines and documentation standards regarding resuscitation care choices (Brown et al., 2014).

There are significant gaps in the literature regarding both the components and location of advance care planning documentation. This may be due in part of the lack of standardization in medical records across practice settings. The Institutes of Medicine (2014, p. 331) has endorsed the integration of technology and electronic health record to improve advance care planning in their publication *Dying in America* in which improvement of integration of electronic health record technology that connects patient’s advance care planning information among care providers and locations. Vital infrastructure is lacking that would allow communication between various electronic health record systems for the purpose of sharing or transferring patient health information, as well documentation frameworks or templates for clinician use (Conn, 2015, March 7).

**Initiating Conversations: Perceptions and Practice Setting**

Both opportunities and barriers have been identified repeatedly in the literature for physicians and nurse practitioners in initiating advance care planning and goals of care conversations. Little, however has been documented about clinical practice setting of practitioners. Additionally, who should take the lead with such conversations, either patients or healthcare providers has been a source of debate. In a recently published article, Lakin et al. (2016) noted that primary care providers may be the logical place for advance planning conversations; however, many patients lack consistent primary care, have multiple specialty
providers and encounter frequent hospital admissions that may increase the confusion as to which clinical specialty should guide such discussions. Anderson, Kools and Lyndon (2013) found that despite unestablished relationships, hospitalist providers can facilitate patient-centered serious illness conversations with hospitalized patients and provide emotional support. There are many opportunities for further study as there is limited published literature regarding serious illness communication by hospital providers as well as the relationship between comfort level and practice setting. It is clear that primary care and acute care providers will need to be increasingly more proficient in initiating and conducting advance care planning and goals of conversation in patients with complex medical problems (Bernacki et al., 2015)

**Theoretical Framework**

In its landmark publication, *Crossing the Quality Chasm*, (2001) the Institutes of Medicine (IOM) proposed six targeted areas of health care improvement for better patient outcomes. Included in these six areas, was the concept of health care that is patient-centered which considers a person’s individual values, beliefs and preferences and incorporates them into the decision-making process and subsequent plan of care (Committee on Quality of Health Care in America, 2001). The open systems theory provides a framework from which health care delivery is influenced through a series of inputs, throughputs and outputs from the internal and external environment (Drenkard, Swartwout, Deyo & O’Neil, 2015). Using the open systems framework, the Interactive Care Model (ICM) was developed with the purpose to promote individual engagement in health care (Drenkard et al., 2015). At the core of the model is the patient and the family with three environmental factors that encompass the main elements or five outputs of the conceptual model known as population and global health, community readiness, practice environment and the healthcare system (Drenkard et al., 2015). There are five elements
to the care model that provide clinicians and providers strategies for promoting a participatory position rather than passive approach by patients and their families (Drenkard et al., 2015). The elements include assess the person’s capacity for engagement, exchange information and communication choices, planning between the person and clinicians, appropriate interventions determined, and evaluate regularly (Drenkard et al., 2015). For the purpose of this study only two domains of this conceptual model will be used as foundational concepts; exchange information and communication choices and planning between the person and clinicians. Refer to Appendix A.

Phase one of the Interactive Care Model involves partnering with patients and their families to promote open communication and shared decision-making which moves away from a paternalistic perspective of care and towards a collaborative approach (Drenkard et al., 2015). This concept requires the clinician to be mindful of the patient’s needs, including cultural, ethnic, or religious in addition to any challenges such as low health literacy when communicating with patients and families (Drenkard et al., 2015). To ensure this approach is effective providers must take an active listening role with patients and families in order to personalize plan of care that best matches their preferences and goals in a true “exchange” of information (Drenkard et al., 2015, p. 506). Once health information has been shared between clinicians, patients and family members, the next step in the process can begin which entails developing a care plan that considers individual needs, values, beliefs, and preferences and considers one’s emotional, physical and spiritual well-being (Drenkard et al., 2015).

You et al., (2015) found that interaction and trusting relationships with providers was ranked as one of the most important factors by patients and their families when engaging in advance care planning conversations. This concept is important for the planning phase of the
Interactive Care Model in developing a patient-centered approach for future goals. For the patient with serious, chronic illness, providers and patients must have a shared understanding of the aims of future care as this is essential for the development of clinical and psychosocial support (Drenkard et al., 2015). Drenkard et al. (2015) contend that patient engagement requires clinician competency and time. The practical application of a care model requires consideration of new skill sets by clinicians, technology innovation and reimbursement for time in care coordination activities. Novel payment systems which include advance care planning as a separate and coverable service for physicians, nurse practitioners and physician assistants by Centers for Medicare and Medicaid Services (CMS) is a progressive step towards promoting provider and patient engagement (CMS, 2015).

Despite challenges such as time, limited patient-provider relationships and difficult subject matter, interprofessional collaboration can enhance the shared-decision making process (Roze de Ordons, Sharma, Heyland & You, 2015). The Interactive Care Model not only fosters a patient-centric approach to care, but encourages the patient and their family to be an integral part of the decision making process. This is a critical point for clinicians when discussing prognosis, patient preferences, values and goals of care with individuals with life-limiting illnesses. The use of a structured, serious, illness conversation guide supports the foundational basis of the ICM in promoting active engagement of patients and their families.

**Methods**

The original study design involved a multi-provider hospitalist practice that consisted of physicians, NPs and PAs conducted in a two-hospital regional healthcare system on the coast of South Carolina. Participants were recruited to complete a survey and attend an in-person educational session on advance care planning and the use of the Serious Illness Conversation
Guide (SICG) developed by Ariadne Labs. See Appendix B. The original proposal involved a survey assessment of hospital provider perceptions, barriers and current practices using the EOLCDQ II questionnaire before and after formal education regarding advance care planning discussions and the use of the serious illness conversation guide. Additionally, a random audit of inpatient medical records from patients with selected chronic, serious illnesses (COPD, CHF or ESRD) was also designed to evaluate documentation of resuscitation status and the presence of advance care planning conversations by hospitalist providers before and after advance care planning education.

In the weeks prior to the implementation of this project, the hospital in which the study was to be conducted, underwent major organizational change. These changes resulted in the termination of the hospitalist services contract, which led to potential study participants leaving the practice group prior to the start of the project. The anticipated sample size was reduced to less than 20 possible participants. The Clinical Informatics Director, who was assisting the PI with the implementation of a documentation template for the providers to enter advance care planning and goals of care discussions into the electronic medical record (EMR), resigned in June 2016. Due to these unforeseen changes, the method for project delivery was reevaluated. After careful consideration, both the sampling procedures and education methods were changed to an anonymous online method from the originally proposed, in-person training sessions.

Due to these organizational changes, the project structure was redesigned to include online recruitment and delivery for the both the EOLCDQ II survey and the educational learning module. To increase sample size, nurse practitioners were recruited from the South Carolina Nurses Association (SCNA) advanced practice registered nurse (APRN) database. An additional
consent was created for the anonymous online survey for nurse practitioner participants. The original sample participants were also invited to participate in the study.

**Protection of Human Subjects**

**Institutional Review Board.** The original project plan was submitted to the Institutional Review Board (IRB) on May 1, 2016. Modifications to the sample and methods of the project design were resubmitted to the IRB on June 3, 2016 with subsequent approval on June 5, 2016. Additional IRB approval was granted from the PIs employer on June 24, 2016.

**Ethical Considerations.** Prior to participating, the principle investigator (PI) provided a detailed explanation of the purpose, design and instructions to all hospitalists and South Carolina nurse practitioner participants via email. The hospitalist providers received an additional printed version of the invitation to participate and flyers were posted in the group’s office. The decision to participate was completely voluntary and had no effect on the providers’ employment. Please see the attached invitation letter, informed consent documents and audit form in Appendices D, E, F, and G.

**Data security.** All electronic data files were stored in an encrypted data file on a password-protected computer. Original documents such as the medical record audit have been entered into an electronic data base with the paper stored in a secured filing-cabinet in a locked office. Medical record audit data was de-identified and coded chronologically with no personally identifying information collected. Access to research data has been limited to the principle investigator and committee advisor.

**Intervention**

The educational intervention was initially designed as a face-to-face professional development presentation with the institutional hospitalists. Due to time constraints and inability
to get training sessions completed before the hospitalist group restructuring occurred at the end of June, an asynchronous educational intervention was developed.

The purpose and content of the online education included advance care planning and the use of the Serious Illness Conversation Guide as originally planned. A copy of the Serious Illness Conversation Guide is included in Appendix B. The video training included a role-playing demonstration of a conversation between a nurse practitioner provider and patient discussing goals of care and preferences. See Appendix C for a complete transcript of the video script.

**Data Collection**

Data collection involved both institutional and individual data collection. Institutional data was restricted to the random medical record audit previously described. Individual subject data collection consisted of the pre- and post-education surveys. SurveyMonkey was used to administer the EOLCDQ II survey and further ensure the anonymity of the participants and their responses.

**Medical record audit.** A medical record audit tool was created to randomly collect data from the participating facility which included de-identified information from patients with COPD, ESRD, CKD or CHF. The audit tool included age, ethnicity, diagnosis, code status, presence of an advance directive and documentation of a serious, illness conversation in the medical record. The audit was completed both before and after the EOLCDQ II survey and education period. See Appendix H for a copy of the medical record audit data collection form.

**End of Life Decision Questionnaire II.** The End of Life Care Decision Questionnaire II (EOLCDQ) was used to anonymously assess beliefs, practices and barriers of physicians, NPs and PAs when engaging in advance care planning discussions (Stoeckle, et al., 1998). The EOLCDQ II measurement tool was originally developed in 1998 by an interprofessional team
led by Dr. Mary Stoeckle with expertise in ethics (Stoeckle, et al., 1998). The original 48-item instrument was used to assess attitudes and barriers to end of life care and discussions among physicians, nurses, social workers and pastoral care associates (Stoeckle, et al., 1998). The EOLCDQ II tool, comprised of two subscales: perceptions of the end of life discussion process and beliefs and practices, included Likert response items ranging from Strongly Agree (SA), Agree (A), Undecided (U), Disagree (D), and Strongly Disagree (DA).

Previous validity and reliability testing indicated the instrument as reliable and appropriate method to assess provider attitudes and perceptions regarding end of life care and practices. Cronbach’s alpha for subscale one, perceptions of the end of life process was 0.85 and 0.69 for subscale two, beliefs and practices. The Cronbach’s alpha for the combined instrument total was 0.82. Further testing using factor analysis was conducted on subscale two, which indicated that three items needed to be deleted. Retesting reliability resulted in 0.73 and 0.84 for this subscale.

For the purposes of this study, the instrument was modified from its original form to include nurse practitioner and physician assistant providers. The instrument required few other modifications to reflect current practice trends including educational background, practice setting and the inclusion of NPs and PAs in the question “who should initiate discussions on end of life discussions.” The phrase “types of clergy” was changed to “spiritual advisor” in the same question. Minor revisions to age, ethnicity, and years of practice were also made to ensure anonymity for participants in the study. Due to the inclusion of nurse practitioners from the state of South Carolina, the question regarding “area of specialty” was changed to “setting best describes your current practice.” Question 10 concerning attendance or participation in any type of training or education regarding Patient Self Determination Act, was modified to include the
phrase “or End of Life Care education.” The remaining questions in subscales 1 and 2, were not be modified. Refer to Appendix I to view the modified EOLCDQ II. Participants were asked to complete the EOLCDQ II survey before and after completing the online educational module. An additional survey question at the end of the EOLCDQ II was used to validate the impact of the educational intervention on perceptions, beliefs and practices by participants. Evaluation of provider perceptions regarding end of life care and conversations based on practice setting and who should initiate end of life conversations were assessed through existing question in the EOLCDQ II survey. Lastly, demographic questions were modified to ensure responses did not reveal a participant’s identity.

**Sampling**

Convenience sampling was used for this study. Physicians, nurse practitioners and physician assistants employed as hospitalist providers in a two-hospital regional health system were invited to participate. Approximately 23 hospitalist providers were initially invited, however after the restructuring announcement, multiple providers resigned their positions. For this reason, additional participants were recruited through the South Carolina Nurses Association (SCNA) advanced practice nursing database. Invitations to participate in the study were sent anonymously to all nurse practitioners in the database by the administrative personnel at the SCNA.

An a priori power analysis was calculated to determine the sample size for a paired t-test. For a two-tailed test with alpha set at .05, beta at .20, an effect size of .50, and a standard deviation of 1.0, a sample size of 31 was needed to perform a paired t-test. The plan included recruitment of 40 participants.
Expenses. The actual expenses for this project were less than originally estimated. Costs were originally projected for $709 for all anticipated supplies and technologies. The actual total amount spent was significantly less due to the lack of live educational sessions and paying for the subscription to SurveyMonkey monthly rather than as an annual fee. Additionally, the PI did not require a separate lockbox for paper medical record chart audits as the PI’s office is equipped with a locking file drawer. See table 8 for detailed expenses. There was no funding awarded or needed for the completion of this study.

Results

Data Preparation and Analysis

Data were analyzed using IBM Statistical Package for the Social Sciences (SPSS) 23. There were no data entry errors, however extensive missing data was found with both random and nonrandom patterns of missingness identified. Missing data was deleted from inferential data analysis (Sainani, 2015; Kim & Mallory, 2014) using pairwise deletion. Eight out of 45 surveys were found to have incomplete data and appeared that study participants failed to complete their questionnaires. Incidentally, the majority of skipped responses were in the Perceptions and Beliefs subscale portion of the survey and subsequently deleted from analysis (Sainani, 2015). Despite the request for participants to complete both a pre- and post-education survey, only five matched pairs were identified. Of these matches, one participant did not finish either of the surveys that were initiated and another participant completed one of two surveys for a total of three matched pairs.

Sample Characteristics

Participating clinicians included nurse practitioners (78.3%), physicians (6.5%) and physician assistants (4.3%) with various educational and religious backgrounds, practice settings
and experience. The majority of participants were females (91.3%) greater than 50 years of age (69.5%). The clinical practice of participants was diverse and included acute/critical care (32.6%), primary care (15.2%) and emergency (2.2%). Many participants responded to working in “other” clinical settings (41.3%) such as gastroenterology, oncology, hospice, and home care. Refer to Table 1 & 2 for detailed participant characteristics.

**Research Questions**

The clinical research questions were developed based on current gaps in literature and practice of known barriers to advance care planning discussions between providers and patients and their families. The purpose of the research project was to examine the impact of perceptions, clinical setting, education and the use of a communication guide on attitudes and practices regarding end of life care conversations.

**Question 1.** Does the use of a serious illness conversation guide by providers during hospitalization increase the number of documented advanced health care planning conversations as compared to not using a conversation guide? There were 21 medical records reviewed prior to the opening of the survey and educational intervention. All records included a diagnosis of at least one chronic serious illness: COPD (n = 10), CHF (n = 7) and advanced kidney disease (n = 4). There was no documentation of advance care planning or goals of care discussions in 20 (95.2%) of the records with the remaining record having incomplete documentation noted. Post-intervention audit revealed no observable change in documentation of serious illness conversations. 12 records were reviewed with 1 (8.3%) chart having evidence of a serious illness conversation, 9 (75%) without evidence of documentation and 2 records with partial or incomplete documentation. Resuscitation status was documented in the electronic medical record
(EMR) as “unknown” in all medical records, both pre- and post-intervention (100%). Refer to Table 3 for complete audit data.

**Question 2.** Will there be a significant change in provider perceptions after implementation of an intensive education program regarding the use of the serious illness conversation guide? The alternate hypothesis for this study proposed there would be a significant difference in the median provider perceptions scores regarding advance care planning discussion before and after formal education. Inferential testing was used to analyze the differences in survey responses regarding providers’ perceptions of end of life care and practices before and after utilizing the Wilcoxon Signed-rank test based on the previously mentioned assumptions. There were no changes in provider perceptions between the pre-education ($Mdn = 27$) and the post-education ($Mdn = 29$) time periods, $z = 1.000, p = .317, r = -.354$.

**Question 3.** What are provider beliefs and practices regarding end of life care and communication? Participants responded to a series of statements assessing their end of life care beliefs and practices. The majority of respondents (76.1%) indicated that their work experience enabled them to discuss end of life care with patients and families, while only two providers responded undecided (2.2%) or strongly disagree (2.2%). Similarly, providers responded they strongly agreed (32.6%) or agreed (41.3%) that their education enabled them to discuss end of life care with patients and their families. The remaining respondents indicated they were undecided (4.3%) if their education prepared them for such discussions. Most participants (54.4%) believed that patients were given options for treatment that were futile and prolonged the dying process. Refer to Table 4.

**Question 4.** Do perceptions regarding end of life care and conversations differ among providers based on practice setting? To determine whether practice setting influenced provider
perceptions, analysis was conducting using one-way ANOVA. There was no significant
difference in perceptions between providers working in acute care, primary care, or other
settings, $F (2, 29) = .600, p = .555$. Analysis of practice setting and beliefs and practices was also
conducted using one-way ANOVA. There was no significant difference in provider beliefs and
practices based on practice setting, $F (2, 27) = 1.339, p = .279$. Refer to tables 5 and 6.

**Question 5.** Who do providers believe should initiate end of life conversations?

Participants were asked to rank ‘who should initiate end of life conversations” from highest (1)
to lowest (9). Respondents (41.3%) ranked patients first as the person who should initiate end of
life discussions, followed by physicians (30.4%) and family (8.7). Only 6.5% of respondents
ranked nurse practitioners as first. Registered nurses, physician assistants and social workers
were not ranked as first by any respondent (0%). See Table 7 for details. The majority of
respondents disagreed (50%) with the statement “I wait for patients or family to initiate end of
life care discussions” while others indicated they strongly agreed (10.9%) or agreed (10.9%)
with the statement. There was no significant difference on waiting for patients or families to
initiate end of life care discussions and type of practice setting, $H (2) 1.380, p = .502$.

**Instrument Reliability**

Reliability testing of the EOLCDQ II instrument was conducted on the sample.
Cronbach’s alpha was 0.677 for the perceptions subscale and 0.684 for the beliefs and practices
subscale. The Cronbach’s alpha for the combined instrument total was 0.457, indicating poor
overall consistency between the survey items.

**Discussion**

There was no observable difference in documentation of advance care planning and goals
of care conversations by providers. This is most likely attributed to the fact that very few
respondents from the hosting facility participated in the pre- and post-intervention in which the medical record audit was conducted. As previously noted, a major organizational change in the contractual relationship with hospitalist providers resulted in an absence of organizational support for the implementation of this project. Consequences included lack of participation by providers and consensus on where documentation of serious illness communication should be housed in the EMR.

The findings regarding provider work experience and education enabling end of life care discussions is inconsistent with current literature. Despite providers answering favorably about their work and education, most participants \((n = 30, 65.2\%)\) indicated that additional education would improve their ability to communicate with patients and their families. Furthermore, the majority of participants indicated that patients often receive “options for treatment that are futile and may prolong the dying process” which may also be inconsistent with participant responses suggesting they do not wait for patients to initiate care discussions. These mixed results may be due to the small sample size and outdated survey questions.

There was no difference for either belief and practices or perceptions based on provider practice setting. Primary care providers had the lowest scores \((M = 26.4)\), indicating they were the most comfortable of the three groups with end of life care discussions. Conversely, acute care providers were least comfortable with a mean score of 29. Providers representing “other” practice settings scored between the two groups \((M = 27.64)\). Given the 10-50 range of the instrument, none of the groups achieved mean scores indicating strong comfort performing this clinical expectation. It is important to note that primary care providers may be under-represented in this study due to small number of respondents \((n = 5)\) in comparison to the larger number of acute care participants \((n = 14)\). To better determine the impact of clinical practice setting on
provider comfort or perceptions and advance care planning conversations, further study that examines specific settings and provider-patient interactions is recommended.

**Implications for practice**

Although the sample was not optimal and changes in the project design were required, the results did reveal several consistent trends regarding end of life perceptions and practices by providers. Inconsistencies in participants’ responses indicate that although providers state that they engage and initiate advance care planning discussions with patients, many survey participants believe that patients or their families should initiate these discussions. This is consistent with current literature (Lakin et al., 2016; Simon et al., 2015; You et al., 2015; Bernacki & Block, 2014; Patel et al., 2011).

The project strongly indicates a need for continuing education for health care providers expected to initiate end of life care planning discussions. To more clearly identify target audience needs, and evaluate educational effectiveness, the current survey tool requires modification or replacement to better reflect current practice trends.

**Project accomplishments.** While not part of the original project design, the creation of an online educational module discussing advance care planning and the use of the Serious Illness Conversation Guide, did reach a larger audience of nurse practitioners within the state of South Carolina. The education consisted of a tutorial as well as a demonstration of a serious illness conversation with goals of care and preferences between a provider and patient (role-playing). In addition, the EOLCDQ II survey was updated to include both physicians and nurse practitioners. The project also allowed for a reassessment of instrument reliability when used with a different health care provider population: advanced practice nurses. This assessment identified a clear need for revision of the tool for future use with this population of health care providers.
Limitations

There were several limitations to this study. Sample size was not optimal, most notably for studying perceptions, beliefs and practices within a hospitalist practice. This was attributed to the organizational and contractual changes that occurred prior to implementation. Additionally, the available timeframe for recruiting, completing the survey and education was limited and also impacted the overall sample size. The efficacy of the online education versus based on pre- and post educational testing for physician and nurse practitioner providers could not be compared. With few before and after surveys completed, it is difficult to assess the true benefit of the self-study education module. This format also removed the opportunity for providers to discuss perceived barriers or give feedback about using the Serious Illness Conversation Guide during the education.

The EOLCDQ II survey was not originally developed for hospitalists or advanced practice providers, such as nurse practitioners or physician assistants. It was developed in 1998 and may no longer be a valid method for measuring perceptions and practice barriers to advance care planning and goals of care conversations in the current clinical context. It must also be considered that the modifications made to the survey tool may have affected the results. Reliability and validity testing indicated that this tool was less reliable for this particular sample comprised mostly of nurse practitioners. The healthcare climate has changed since the original development of this instrument and it is possible that wording is no longer valid in measuring end of life experiences and opinions by clinicians. Furthermore, it would appear that other factors may have influenced the perceptions, beliefs and practices of participants that were not measured on this survey.

Recommendations for practice
Although there were unforeseen obstacles which resulted in the modifying design and implementation of this study, the information learned has provided an opportunity for further scholarship. Several recommendations for clinical practice are evident. Consistent with previous literature, there are inconsistencies with timing of serious illness communication and whom providers believe should initiate these conversations. Furthermore, providers perceive that additional education would be beneficial for improving end of life communication with patients and families. These findings support the need for formalized education regarding serious illness communication and goals of care in both medical and nurse practitioner programs. Incorporating structured training into nurse practitioner education may increase clinician confidence and skills while improving patient outcomes (Lakin et al., 2016; Bernacki, et al., 2015; Sinuff et al., 2015; You et al., 2014; Downar & Hawryluck, 2010). Interprofessional education through simulation may also have potential benefit in advance care planning communication training in formal nurse practitioner and medical curricula (Curtis et al., 2013). Developing a didactic and face-to-face education program which utilizes role playing may benefit novice nurse practitioners focusing on patient-focused language, prognostication, and timing of these discussions.

An additional recommendation is ongoing quality improvement at the hosting facility to improve advance care planning conversations in select populations as well as improving the documentation of patient preferences for care. Work should include ongoing education with hospitalist staff, auditing of chart data and eliciting the support of the hospital administration and additional clinical specialties and services. It is further recommended that continued efforts regarding serious illness and goals of care communication be made an institutional quality improvement priority.
Future study must explore why clinicians prefer patient or family members initiating advance care planning discussions. Additional research should include investigation of the content of conversations and the most effective methods for clinician initiation based on condition of the client and setting. Additional assessment of barriers to serious illness conversations, particularly in acute care settings, using current language may also assist in a better understanding of clinicians’ perceptions. It is important that providers collaborate with patients and their families to promote shared-decision making prior to critical illness. This requires conversations that often provoke emotional responses in both patients and providers. In order to better advocate for patients and their families, clinicians must possess the skills to engage in serious illness and goals of care conversations to ensure patient-centric outcomes.
References


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systematic review of quantitative studies identifying the elements of end-of-life care that patients and their families rank as being most important. *Palliative Medicine, 29*(9), 774-796. doi:10.1177/0269216315583032


Table 1

Demographic characteristics of participants

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Table 2

Professional characteristics of participants

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### Table 3

**Pre- and Post-intervention audit data**

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<td>COPD</td>
<td>10</td>
<td>47.6</td>
</tr>
<tr>
<td><strong>Resuscitation Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unknown</td>
<td>21</td>
<td>100</td>
</tr>
<tr>
<td><strong>Does patient have Advance Directive (AD)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>13</td>
<td>61.9</td>
</tr>
<tr>
<td>No</td>
<td>8</td>
<td>38.1</td>
</tr>
<tr>
<td><strong>Advance Directive (AD) present in record</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>3</td>
<td>14.3</td>
</tr>
<tr>
<td>No</td>
<td>10</td>
<td>47.6</td>
</tr>
<tr>
<td>N/A</td>
<td>8</td>
<td>38.1</td>
</tr>
<tr>
<td><strong>Serious Illness documentation in EMR</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>No</td>
<td>20</td>
<td>95.2</td>
</tr>
<tr>
<td>Partial/incomplete</td>
<td>1</td>
<td>4.8</td>
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</table>
Table 4

Belief and practices subscale: Participant responses

<table>
<thead>
<tr>
<th>Question</th>
<th>Participant responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>I believe my work experience enables me to discuss end of life care with patients and family</td>
<td>Strongly Agree 20 (43.5%)</td>
</tr>
<tr>
<td>I believe my education enables me to discuss end of life care with patients and family</td>
<td>Strongly Agree 15 (32.6%)</td>
</tr>
<tr>
<td>I feel comfortable using the words die/death when discussing end of life care with my patients or families</td>
<td>Strongly Agree 13 (28.3%)</td>
</tr>
<tr>
<td>End of life care discussions facilitate physician-family agreement on treatment choices</td>
<td>Strongly Agree 14 (30.4%)</td>
</tr>
<tr>
<td>I frequently discuss pain control for my terminally ill patients’ with nurses/physicians</td>
<td>Strongly Agree 11 (23.9%)</td>
</tr>
<tr>
<td>All patients, even if they are not terminally ill, have the right to make decisions regarding end of life care (life support) even if that decision may lead to death</td>
<td>Strongly Agree 21 (45.7%)</td>
</tr>
<tr>
<td>I frequently discuss pain control for my terminally ill patients</td>
<td>Strongly Agree 12 (26.1%)</td>
</tr>
<tr>
<td>Patients and families are often given for treatment that are futile and prolong the dying process</td>
<td>Strongly Agree 5 (10.9%)</td>
</tr>
<tr>
<td>I wait for the patient or family to initiate end of life care discussions</td>
<td>Strongly Agree 5 (10.9%)</td>
</tr>
<tr>
<td>I frequently collaborate with other healthcare professionals to facilitate end of life care decisions</td>
<td>Strongly Agree 15 (32.6%)</td>
</tr>
</tbody>
</table>
Table 5

*Practice Influence on Perceptions*

<table>
<thead>
<tr>
<th></th>
<th>Sum of Squares</th>
<th>df</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Between Groups</td>
<td>45.236</td>
<td>2</td>
<td>22.618</td>
<td>1.339</td>
<td>.279</td>
</tr>
<tr>
<td>Within Groups</td>
<td>456.231</td>
<td>27</td>
<td>16.897</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>501.467</td>
<td>29</td>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>
Table 6

*Practice Influence on Belief and Practices*

<table>
<thead>
<tr>
<th></th>
<th>Sum of Squares</th>
<th>df</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Between Groups</strong></td>
<td>27.586</td>
<td>2</td>
<td>13.793</td>
<td>.600</td>
<td>.555</td>
</tr>
<tr>
<td><strong>Within Groups</strong></td>
<td>666.414</td>
<td>29</td>
<td>22.980</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>694.000</td>
<td>31</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 7

Who Should Initiate End of Life Conversation Frequencies

<table>
<thead>
<tr>
<th></th>
<th>Ranking</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1 n (%)</td>
</tr>
<tr>
<td>Patient</td>
<td></td>
</tr>
<tr>
<td></td>
<td>19 (41.3)</td>
</tr>
<tr>
<td>Patient’s Family</td>
<td></td>
</tr>
<tr>
<td></td>
<td>4 (8.7)</td>
</tr>
<tr>
<td>Spiritual Advisor</td>
<td></td>
</tr>
<tr>
<td></td>
<td>0 (0)</td>
</tr>
<tr>
<td>Physician</td>
<td></td>
</tr>
<tr>
<td></td>
<td>14 (30.4)</td>
</tr>
<tr>
<td>Nurse Practitioner</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3 (6.5)</td>
</tr>
<tr>
<td>Registered Nurse</td>
<td></td>
</tr>
<tr>
<td></td>
<td>0 (0)</td>
</tr>
<tr>
<td>Physician’s Assistant</td>
<td></td>
</tr>
<tr>
<td></td>
<td>0 (0)</td>
</tr>
<tr>
<td>Social Worker</td>
<td></td>
</tr>
<tr>
<td></td>
<td>0 (0)</td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2 (4.3)</td>
</tr>
</tbody>
</table>
Table 8

*Supplies and Costs related to DNP Project Implementation*

<table>
<thead>
<tr>
<th>Item</th>
<th>Purpose</th>
<th>Actual Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>SurveyMonkey Inc.</td>
<td>To electronically administer the survey</td>
<td>$104</td>
</tr>
<tr>
<td>Measurement &amp; instruments book</td>
<td>For researching appropriate instruments for DNP project</td>
<td>$84</td>
</tr>
<tr>
<td>Staples printing services</td>
<td>Printing the Serious Illness Conversation guides, pocket cards and project flyers</td>
<td>$22.84</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>$210.84</td>
</tr>
</tbody>
</table>
INTERACTIVE CARE MODEL

Rethinking the person/family/care partner and clinician relationship to better engage people in their health care journey.
Appendix B

Serious Illness Conversation Guide

1. Set up the conversation
   - Introduce the idea and benefits
   - Ask permission

2. Assess illness understanding and information preferences

3. Share prognosis
   - Tailor information to patient preference
   - Allow silence, explore emotion

4. Explore key topics
   - Goals
   - Fears and worries
   - Sources of strength
   - Critical abilities
   - Tradeoffs
   - Family

5. Close the conversation
   - Summarize what you’ve heard
   - Make a recommendation
   - Affirm your commitment to the patient

6. Document your conversation
“I’m hoping we can talk about where things are with your illness and where they might be going — is this okay?”

“What is your understanding now of where you are with your illness?”

“How much information about what is likely to be ahead with your illness would you like from me?”

Prognosis: “I’m worried that time may be short.”
or “This may be as strong as you feel.”

“What are your most important goals if your health situation worsens?”

“What are your biggest fears and worries about the future with your health?”

“What gives you strength as you think about the future with your illness?”

“What abilities are so critical to your life that you can’t imagine living without them?”

“If you become sicker, how much are you willing to go through for the possibility of gaining more time?”

“How much does your family know about your priorities and wishes?”

“It sounds like __________ is very important to you.”

“Given your goals and priorities and what we know about your illness at this stage, I recommend…”

“We’re in this together.”
Serious Illness Communication & Advance Care Planning for Hospital Providers
Education Script

Slide 1 – Hello and welcome to the Serious Illness Communication & Advance Care Planning for Hospital Providers training session. My name is Kelly Bouthilet and I am doctoral candidate at Georgia College. You have been invited to participate in this translational research and clinical practice project which includes a survey about end of life practices and perceptions and this online training session.

Slide 2 – Please be sure to take End of Life Care Decision Questionnaire II Assessment Survey before viewing this training.
- Once you have completed this training session, please follow the link to the survey and retake the survey. To confirm, I am requesting a before and after survey.

Slide 3 – The following objectives will be discussed during the course of this training session.
- Discuss the concept of advance care planning in the context of chronic serious illness
- Identify barriers for providers in advanced care and end-of-life planning
- Explore communication strategies for discussing end-of-life with patients and families

Slide 4 - There are many issues that contribute to the fragmented care that patients may receive in the hospital, this may be confounded by serious complex conditions and preparing for end of life care.
- Many patients often get caught in a revolving-door of hospitalizations without a clear plan for future care
- Despite the Patient Self Determination Act, hospitals continue to struggle with adequately obtaining advance directive information and providing education to patients and clinicians alike
- Numerous obstacles have been cited in the literature including barriers to communication with patients and failure to collect or record resuscitation status, and obtain other important advance care planning documentation in the medical record
- Inadequacies in or lack of discussions regarding end of life care, can result in miscommunication, poor patient outcomes and future uncertainties in care for the patient

Slide 5 – So what are some of the issues that bring us to this point?
- Chronically ill patients are subject to frequent, episodic acute hospitalizations without any future care planning
- We know that Medicare spending is exponentially increased during the last 6 months of a person’s life despite any clear direction or provisions
- In a major national health study, researchers found that the majority of participants had no end of life care planning and no surrogate decision maker appointed
- These findings are interesting in the context that in the same study, most participants had concerns about future end of life care including: pain, costs of care and preservation of dignity and comfort

Developed by K. Bouthilet May 2016
Slide 6 – How do we know that this is an issue?
- Inpatient survival from cardiac arrest remains variable between 18-26%
- Only 26% of population has elected any type of end of life care planning
- Once in the hospital setting, an unknown code status often results in default “full code” status regardless of patients’ preferences
  - Fragmented discussions and lack of documentation contribute further confusion
- For individuals with serious chronic conditions, care becomes episodic due to exacerbations and is often void of any meaningful discussions or long-term planning despite repeated interactions with care providers
- As clinicians, we are often uncomfortable to start the conversation about the future course of their disease with patients
  - Literature confirms that most physicians and nurse providers never received formalized training in their education programs on end of life care or conversations

Slide 7 – Chronic, serious illness refers to any disease process that is progressive in nature and is life threatening
- Commonly encountered conditions include:
  - Advanced Chronic Obstructive Pulmonary Disease (COPD)
  - Heart Failure, class III or IV
  - Chronic Kidney Disease (CKD) & End Stage Renal Failure
  - Cancer
- For the purpose of this training, the term serious illness will refer or include one of these conditions

Slide 8 – It is important to discuss some commonly used terms that are often confused with the phrase “advanced care planning.” While planning is a process, the following are forms or legal documents that aid providing a legal record of health care decisions.
- The POLST or physician orders for life-sustaining treatment is a document that specifies directives in the event in an emergency to the types of life-saving care an individual wishes to receive
  - Usually prepared for individuals with serious, life-limiting illness, generally less than a year to live
  - Not all states have established POLST programs and State DNR forms are required
- The advance directive is a legal document that records a person’s desires regarding future health care, and can be very detailed or limited; this is usually prepared during a time of better health
  - It may also be referred to as a Living will
- Health care power of attorney – a legal document that names a person designated to speak on your behalf
  - The term Health care proxy is also used

Slide 9 – Advance care planning is a patient-centric approach to communication pertaining to future health needs and goals of care, especially end of life care planning
It is important to consider personal values or religious preferences of patients when discussing serious illnesses, prognosis and goals of care. It is not a form and care decisions may be made over several conversations and may evolve over time.

Slide 10 – It is well documented in the literature that most clinicians find discussing end of life care planning difficult or uncomfortable.
- There have been many barriers noted from both the patient and provider perspectives.
- For health care providers there are no uniform standards or guidelines as to what the components of communication should include.
- Additionally, time and who is responsible for the discussion are often factors cited for not engaging in these conversations.
- It is important for clinicians to become familiar and comfortable with advance care planning and goals of care language to better serve our patients.

Slide 11 – Although it seems counterintuitive, discussing illness trajectory and prognosis is good for both the patient and their family. The benefits of these discussions include:
- Goal-oriented care
- Time to fulfill personal goals
- Improved quality of life
- Higher patient satisfaction
- More and earlier palliative or hospice care
- Fewer acute care hospitalizations
- Better patient and family coping
- And eased burden of decision making for families

Slide 12 – The outcomes of advance care planning discussions include providing patients with information regarding their health and allowing them to be active participants. Most patients want to know about their prognosis and may have less anxiety and depression.

Slide 13 – There are some key principles the provider should keep in mind when having end of life and goals of care discussions with patients.
- Patients want the truth about their diagnosis
- Anxiety is normal for both the clinician and the patient
- Many patients have goals and priorities besides living longer, knowing them allows for better care to be provided
- The opportunity to express fears and worries is therapeutic
- Be sure to give honest and direct answers to the patient and allow for periods of silence
- Acknowledge the patient’s emotions and explore them
- And finally document the conversation

Slide 14 - So let’s discuss the Serious Illness Conversation Guide and utilizing an organized approach to these often difficult discussions.
- The guide is divided into 2 sections; on the left side is the clinician steps while the right side has the conversation guide
As indicated on the left, the clinician steps include SET UP to introduce the conversation. On the right side, the guide provides language to help you discuss critical topics.

Slide 15 – When initiating the conversation with the patient, it is important to consider timing as the optimal time to introduce a discussion of values and goals is then the patient is relatively stable and not in a current medical crisis.

- Remember to use the SET UP prompts on the left to guide you through the sequence of the conversation.
- See how the guide provides prompts with the purpose and suggested language for that element.

Slide 16 – To assess illness understanding and information preferences, ask the patient what they know and how much information they want to receive again, using the suggested language to guide the conversation.

Slide 17 – Discussion of prognosis it often the most difficult part due to the uncertainty or concern of provoking a strong emotional response from the patient. Remember, most patients want to know their prognosis and know that clinicians cannot give them perfect answers. Be sure to give time in a range, weeks to months, 1-2 years, etc.

Slide 18 – Be prepared for emotion or strong response. Give the patient time to reflect; silence is okay. Respond to any strong emotional response by naming it and exploring. If a patient does not want to discuss further, acknowledge and suggest a break in the conversation and offer to proceed at another time.

Slide 19 – In this part of the conversation, the clinician asks about the patient’s goals and priorities as well as fears and worries. Let the patient express what is important to them about their health and future goals.

- The suggested language asks open-ended questions to elicit more information from the patient.

Slide 20 – The last three questions address what functional abilities, tradeoffs, and family knowledge is important in the current discussion.

- What abilities are so critical to your life that you can’t imagine living without them?
- How much are you willing to go through for the possibility of gaining more time?
- How much does your family know about your priorities and wishes?

Slide 21 – On the left hand side of the guide, the clinician is called to Act on the information discussed. Please note that these may occur at any sequence during the conversation.

- Affirm the commitment to the patient.
- Summarize key goals and priorities.
- Recommend next steps.
- Document the conversation.

Slide 22 – The discussion of code status should remain in context with the current discussion which includes prognosis, values and goals.
• Be sure to assess the patient’s understanding of CPR
  • Correct any misunderstandings and describe risks & benefits
• Make a recommendation regarding resuscitation based on the patient’s prognosis and preferences; something like:
  • “Based on our conversation today regarding the progression of your COPD and the understanding that mechanical ventilation will not improve your lung disease, I recommend that we continue to focus on maintaining your comfort and helping you have as much time as possible with your family?”
• Confirm the patient agrees, “How does this plan sound to you?”
• Emphasize the care that will be provided
  • Supportive care such as pain management or breathing treatments

Slide 23 – Equally as important as the conversation, is the documentation of the same. Documentation should include:
• All participants, including health care POA or shared-decision makers
• The patient’s ability to understand or level of cognition
  • Is there a history of dementia that affects decision making?
• Discussion of the of the illness and prognosis and the patient’s level of understanding
• Preferences for any and all care that was discussed
  • Include any treatments versus palliation
  • Resuscitation Status, if applicable
• Presence of advance directive available
Be sure to include in the documentation if no decisions were made or if the conversation ended prematurely.

Slide 24 – Here is a short video demonstration of a serious illness conversation:

Slide 25 – Additional resources can be found on the world wide web:
• A demonstration of the Serious Illness Conversation Guide by Dr. Block can be viewed by following the links provided
• Information about the serious illness practice work can be found at Ariadne Labs at the link below
• In the article Communication about Serious Illness Care Goals, Drs. Bernacki and Block discuss the inception of the communication guide, common practice barriers encountered in the clinical setting and approaches to goals of care and end of life planning.

Slide 26 – I kindly thank you for viewing this educational session on serious illness communication and advance care planning. I hope it will be beneficial to your practice.
• Please follow the link provided to re-take the survey
• If you have any comments, questions or concerns please contact me at kelly.bouthillet@bobcats.gcsu.edu.
• Thank you again for your time.

Slide 27 – 29 – References
GEORGIA COLLEGE Informed Consent Form

Protocol Director: Kelly Bouthillet MSN, APRN, CCNS, ACNP-BC

Protocol Title: The Effect of a Serious Illness Communication Guide on Provider Perceptions and Advance Care Planning Conversations

PURPOSE OF RESEARCH

You are invited to participate in a research study to assess provider attitudes and perceptions regarding end of life care and practices as well as improve communication between patients and providers in individuals with chronic, serious illness.

VOLUNTARY PARTICIPATION

You were selected as a possible participant in this study because you are currently employed as a provider in the hospital setting. Participation in this study is completely voluntary.

INCLUSION AND EXCLUSION CRITERIA

Please carefully read through the inclusion and exclusion criteria below. By signing this informed consent, you are acknowledging that you have read and agree to the inclusion criteria.

Inclusion Criteria:

- Male or female aged 25 years and older
- English proficiency
- Access to computer with Internet
- Willingness to participate in the survey and training session
- Willingness to sign an informed consent

Exclusion Criteria:

- Providers from other clinical services and bedside nurses
- No access to Internet survey

DURATION OF STUDY INVOLVEMENT

Participation will be asynchronous and will be over a 2-week time period. The before and after survey, as well as online training can be accessed anytime during the 2-week time frame.
PROCEDURES

If you choose to participate, you will be provided a link to SurveyMonkey to complete the End of Life Decisions Care Questionnaire II (EOLCDQ II). The estimated completion time is 15 minutes. An online educational sessions regarding advance care planning and goals of care conversations will be provided for participants and will take approximately 30 minutes to complete. Participants are requested to view the training session. A post-educational survey will be requested after advance care planning training has been completed for reassessment.

Risks:

There are no known risks associated with participation in this survey.

Please note: the survey results will remain anonymous and will not be linked with your name. The intention of the survey is for research purposes only. The results of this survey will be used to support the implementation of a serious illness communication guide to improve advance care planning conversations between providers and patients.

PARTICIPANT RESPONSIBILITIES

As a participant, your responsibilities include:

- Read, sign, scan and return the informed consent via email to kelly.bouthillet@bobcats.gcsu.edu. Please keep a copy for your reference.
- Complete the EOLCDQ II questionnaire via the SurveyMonkey link
- Participate in the online asynchronous Serious Illness Communication & Advance Care Planning training session
- Complete post-education survey

WITHDRAWAL FROM STUDY

If you agree to participate in this study however, in the event you change your mind, you are free to withdraw your consent and discontinue your participation at any time. If you decide to withdraw participation in this study, please notify Kelly Bouthillet via kelly.bouthillet@bobcats.gcsu.edu

POTENTIAL BENEFITS

The potential benefits of this study include awareness by participants of self-perceptions regarding end of life care practices as well as improved communication with chronic, seriously ill patients.
PARTICIPANT’S RIGHTS

You have the right to decide to participate in the survey and may decide to withdraw at any time. Withdrawal or declining to participate in the study, will not influence or effect your employment in any way. In addition, if you have any questions or concerns or decide you no longer wish to participate, please contact the researcher, Kelly Bouthillet.

FINANCIAL CONSIDERATIONS

There are no financial costs associated with participating in this study.

CONFIDENTIALITY

The purpose of this research study is to assess provider attitudes and perceptions regarding end of life care and practices as well as improve communication between providers and patients with chronic, serious illness. The results and findings of this study may be disseminated as aggregate data in peer-reviewed journals, healthcare conferences, and poster presentations. Your identity will not be disclosed in any portion of the project.

__________________________________________
Signature of Adult Participant

Date

Research at Georgia College involving human participants is carried out under the oversight of the Institutional Review Board. Address questions or problems regarding these activities to Dr. Tsu-Ming Chiang, GC IRB Chair, CBX 090, GC, email: irb@gcsu.edu; phone: (478) 445-0863.
Appendix E

INFORMED CONSENT for Nurse Practitioners

The Effect of a Serious Illness Communication Guide on Provider Perceptions and Advance Care Planning Conversations with Patients

You are being invited to participate in a research study to assess provider attitudes and perceptions regarding end of life care and practices as well as improve communication between patients and providers in individuals with chronic, serious illness. This study is being conducted by Kelly A. Bouthillet, MSN, APRN, CCNS, ACNP-BC, Doctorate candidate at Georgia College.

You were selected as a possible participant in this study because you are currently employed as a nurse practitioner provider. Participation in this study is completely voluntary.

The questionnaire(s) will take approximately 15 minutes to complete.

This survey is completely anonymous. Do not indicate your name on the survey. No one will be able to identify you or your answers, and no one will know whether or not you participated in the study and no IP addresses are being collected. No other information is being collected other than your survey responses.

Your participation in this study is voluntary. By proceeding and continuing with this survey, you are voluntarily agreeing to participate and you are acknowledging that you are 18 years of age or older. You are free to stop answering questions at any time or to decline to answer any particular question you do not wish to answer for any reason. If you are younger than 18, do not proceed.

If you agree to participate in this study however, in the event you change your mind, you are free to withdraw your consent and discontinue your participation at any time. If you decide to withdraw participation in this study or have any other concerns, please notify Kelly Bouthillet via kelly.bouthillet@bobcats.gcsu.edu

*Research at Georgia College involving human participants is carried out under the oversight of the Institutional Review Board. Address questions or problems regarding these activities to Dr. Tsu-Ming Chiang, GC IRB Chair, CBX 090, GC, email: irb@gcsu.edu; phone: (478) 445-0863.*
You are being invited to participate in research project to examine the effectiveness of a structured training program on end of life conversations with hospitalist providers including physicians, nurse practitioners and physician assistants. A secondary aim of this study is to identify perceived barriers and facilitators in advance care planning conversations in the acute care setting. By improving self-awareness, providers may exhibit increased confidence in end of life and goals of care discussions. This project seeks to improve the initiation of advance care planning discussions during the hospital admission process with individuals with selected serious, chronic diseases using a conversation guide. An overall objective of this study is to determine if a structured communication approach between hospital providers and their patients results in patient-centered choices for determining future treatment trajectory and end of life care.

Participation in this study is voluntary; however, your opinion is extremely valuable. This research study will be conducted over a 2-week period, although your time commitment is very limited. As a participant of the study, you will be asked to partake in a pre and post survey and view a virtual training session regarding advanced care planning communication. The surveys will take approximately 15 minutes to complete while the virtual training session will be about 30 minutes.

Please see the inclusion and exclusion criteria below to see if you may qualify. If you have any questions or concerns please email kelly.bouthilet@bobcats.gcu.edu for more information.

Participant invitations and consents will be sent out very soon. Thank you for your consideration of participation.

Inclusion Criteria:
- Hospitalist provider service
- English proficiency
- Computer access with Internet
- Willingness to participate in the survey and educational session
- Be willing to sign an informed consent

Exclusion Criteria:
- Providers from other clinical services and bedside nurses
- Non-English speaking providers
- Lack of access to computer and/or Internet survey
- Refusal to participate in either the survey, educational session or sign informed consent

The following links will take you to both the survey and the virtual, online training session. Thank you for your participation in this very important project.

Survey Link: [https://www.surveymonkey.com/r/H5PjL5N](https://www.surveymonkey.com/r/H5PjL5N)

Training Session: [https://vimeo.com/171831029](https://vimeo.com/171831029) Password required: Illness

The survey will be open from June 25th, 2016 through 7/11/16 @ midnight

If you have any questions or concerns please email kelly.bouthilet@bobcats.gcu.edu for more information.

*It's always too early, until it's too late.*

-The Conversation Project, 2013
Appendix G

SERIOUS ILLNESS COMMUNICATION GUIDE & ADVANCE CARE PLANNING CONVERSATIONS

Dear Advanced Practice Registered Nurse Provider,

As a doctoral candidate at Georgia College, I am conducting a translational research and clinical project regarding advance care planning discussions in patients with serious, chronic illnesses.

The purpose of this research project is to identify perceived barriers and facilitators in advance care planning conversations in acute care settings. A secondary aim of this study is to examine the effectiveness of a training program on end of life conversations between providers, patients, and families. By improving self-awareness, providers may exhibit increased confidence in end of life and goals of care discussions. This project seeks to improve the initiation of advance care planning discussions during the hospital admission process with individuals with selected serious, chronic diseases using a conversation guide. An overall objective of this study is to determine if a structured communication approach between hospital providers and their patients results in patient-centered choices for determining future treatment trajectory and end of life care.

Participation in this study is voluntary; however, your opinion is extremely valuable. This research study will be conducted over a 2-week period, although your time commitment is very limited. As a participant of the study, you will be asked to partake in a pre and post survey and view a virtual training session regarding advanced care planning communication. The surveys will take approximately 15 minutes to complete while the virtual training session will be about 30 minutes.

Please see the inclusion and exclusion criteria below to see if you may qualify.

Inclusion Criteria:

- Nurse practitioner provider
- Computer access with Internet
- Willingness to participate in the online survey and virtual training session
- Willing to acknowledge informed consent at the beginning of survey

Exclusion Criteria:

- Refusal to participate in either the survey, educational session or acknowledge informed consent

The following links will take you to both the survey and the virtual, online training session. Thank you for your participation in this very important project.

Survey Link: https://www.surveymonkey.com/r/I5PJL5N

Training Session: https://vimeo.com/171831029 Password required: Illness

The survey and training will be open from June 26th through July 7 @ 12 MN.

If you have any questions or concerns, please email directly kelly.bouthilet@bobcats.gcsu.edu for more information.

It's always too early, until it's too late.
- The Conversation Project, 2013

This study is part of a Doctorate of Nursing Practice Translational Research & Clinical Practice Project
Appendix H

Bouthillet DNP Project: Medical Record Data Collection Form

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<thead>
<tr>
<th>Encounter (De-identified)</th>
<th>Age</th>
<th>Ethnicity</th>
<th>Diagnosis</th>
<th>Code Status</th>
<th>Does the patient have an Advance Directive?</th>
<th>Is the Advanced Directive on chart?</th>
<th>Documentation of Serious Illness Conversation/Plan of Care in regards to life-sustaining treatment in medical record</th>
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Appendix I

End of Life Care Decisions Questionnaire (EOLCDQ II)

"By completing this questionnaire, I indicate my consent to participate in this study. I understand confidentiality will be maintained."

1. To allow for statistical analysis, please create a unique identification that only you know and allows anonymity. Please use the first 3 letters of your mother’s maiden name and the last 3 numbers of your zip code. For instance, MAR926. Please remember this unique identifier for the post-education survey. Thank you.

   [ ]

2. Age:
   - ____ 25-29
   - ____ 30-34
   - ____ 35-39
   - ____ 40-44
   - ____ 45-49
   - ____ 50-54
   - ____ 55-59
   - ____ 60-64
   - ____ 65 or older

3. Gender:
   - ____ Male
   - ____ Female

4. Ethnicity:
   - ____ African American
   - ____ Native American
   - ____ Caucasian
   - ____ Hispanic (Non-White)
   - ____ Other

5. Marital Status:
   - ____ Married
   - ____ Divorced
   - ____ Single
   - ____ Widowed
   - ____ Separated

6. Religious Affiliation:
   - ____ Atheist
   - ____ Catholic
7. **Profession:**

- ___ Physician
- ___ Nurse Practitioner
- ___ Physician Assistant

8. **Highest level of education completed:**

- ___ PhD
- ___ MD
- ___ DO
- ___ MSN
- ___ Other Master’s degree
- ___ Other: Specify _________

9. **What setting best describes your current practice:**

- ___ Primary care
- ___ Acute/critical care (hospital)
- ___ Emergency
- ___ Long term care
- ___ Long term acute care
- ___ Other, please specify

10. **Years of experience as a clinical provider:**

- ___ 5 years or less
- ___ 6-10 years
- ___ 11-15 years
- ___ 16-20
- ___ Greater than 20
- ___ 11-15 years

11. **Have you ever attended a course, seminar, or workshop on the Patient Self Determination Act or End of Life Care education?**

- ___ Yes
- ___ No (If no, skip #13)

12. **If yes, was this mandatory to fulfill a degree, work, or continuing education requirement?**

- ___ Yes
- ___ No

13. **Have you ever attended a course, seminar, or workshop concerning values, ethical, or moral development?**
If yes, was this mandatory to fulfill a degree, work, or continuing education requirement?

- Yes
- No

Have you, a family member, or a close friend ever had a life threatening experience or terminal illness?

- Yes
- No

Has this life threatening experience or experience with terminal illness changed your beliefs, values, or attitude about death and dying?

- Yes
- No

Has your personal experience with a life threatening event or terminal illness changed the way you approach end of life care discussions with patients and families?

- Yes
- No

Have you discussed your end of life care wishes with your family?

- Yes
- No

Have you completed advanced directives for yourself?

- Yes
- No

Do you know your family's end of life care wishes?

- Yes
- No

Have any of your family members completed advanced directives?

- Yes
- No

A living will is a document that identifies what medical treatment you choose to omit or refuse in the event that you are unable to make those decisions for yourself AND are terminally ill.

- Agree
- Disagree
- Unsure

The definition of a durable power of attorney for healthcare is: appointment of a proxy to make medical decisions on your behalf when you can no longer decide for yourself.

- Agree
- Disagree
- Unsure
24. A durable power of attorney for healthcare applies when any illness or injury leaves you mentally incapacitated.

_____ Agree  _____ Disagree  _____ Unsure

25. There is no ethical difference between withholding life support measures or withdrawing these measures once started.

_____ Agree  _____ Disagree  _____ Unsure

26. Have you ever initiated a discussion about end of life decisions with patients or patients' families? If no, skip to #28

_____ Yes  _____ No

27. If yes, how many times have you initiated these discussions:

____ less than 10  ____ 30-39  ____ 60-69  ____ 90-99

____ 10-19  ____ 40-49  ____ 70-79  ____ 100 or greater

____ 20-29  ____ 50-59  ____ 80-89  ____ With ALL patients

28. How comfortable do you feel initiating end of life discussions with your patients?

_____ Very comfortable  _____ Somewhat comfortable  _____ Not comfortable at all

29. Do you think that additional education would enhance your ability to communicate with patients and families about end of life care?

_____ Agree  _____ Disagree  _____ Unsure

30. Whom do you think should initiate discussions on end of life decisions? Please rank the following person(s) from 1=highest priority to 9=lowest priority, use 0=NA (use each number only once).

____ Physician  ____ Nurse Practitioner

____ Physician Assistant  ____ Registered Nurse

____ Social Worker  ____ Spiritual Advisor

____ Patient  ____ Patient's Family

____ Other: Specify
Please read each statement concerning End of Life Care Decisions. Take your time and think about what each statement says. Beside each statement is a scale which ranges from strongly agree (SA) to strongly disagree (SD). For each item we would like you to circle the letters that represent the extent to which you agree or disagree with each statement. Please make sure that you answer EVERY ITEM and that you circle ONLY ONE letter(s) per item. Thank you for taking the time to complete this questionnaire.

SA = Strongly Agree  
A = Agree  
U = Undecided  
D = Disagree  
SD = Strongly Disagree

31. I believe my work experience enables me to discuss end of life care with patients and families.  
   SA A U D SD

32. I believe my education enables me to discuss end of life care with patients and families.  
   SA A U D SD

33. I feel comfortable using the words die/death when discussing end of life care with my patients or families.  
   SA A U D SD

34. Health care professionals provide patients and families with adequate information about end of life care choices.  
   SA A U D SD

35. The patient's wishes and details of end of life care discussions are recorded in the provider progress notes.  
   SA A U D SD

36. End of life care discussions facilitate physician-family agreement on treatment choices.  
   SA A U D SD

37. Terminally ill patients have adequate pain control.  
   SA A U D SD

38. The patient's wishes and details of end of life care  
   SA A U D SD
discussions are recorded in the nursing notes.

39. Patients understand the information they are given about end of life care.

40. I frequently discuss pain control for my terminally ill patients with nurses/physicians.

41. All patients, even if they are not terminally ill, have the right to make decisions regarding end of life care (life support) even if that decision may lead to death.

42. Patients and families are given consistent information about the consequences of their end of life care decisions.

43. I frequently discuss pain control with my terminally ill patients.

44. Terminally ill patients have adequate resources available for evaluating pain.

45. Patients and families are often given options for treatment that are futile and prolong the dying process.

46. Patients and families are given adequate time for the process of making end of life care decisions.

47. I wait for the patient or family to initiate end of life care discussions.

48. I frequently collaborate with other healthcare professionals to facilitate end of life care decisions.

49. I believe patients and families are approached about end of life care decisions in an atmosphere that is nonthreatening and conducive to processing difficult
decisions.

50. Patients and families are regularly included in update discussions regarding their end of life care decisions.

51. POST-TRAINING SURVEY QUESTION:

After completing the online virtual education, please evaluate the effectiveness of training:

The training on the serious illness conversation guide and advance care planning will be beneficial to my clinical practice.

SA  A  U  D  SD N/A, I have not yet completed the training.

Thank you for your time.